STATE COUNCIL FOR PERSONS WITH DISABILITIES' BRAIN INJURY COMMITTEE

May 2, 2016 – 2:00 PM Smyrna Rest Area Conference Room, Smyrna

PRESENT: Ron Sarg, DMD, DE Commission of Veterans Affairs (DCVA); Tammy Clifton, DVR/BIAD; Sharon Lyons, BIAD; Dr. Katie Freeman, DPBHS; Maria Zakula, BIAD; Nicol Joseph, Health Option; Ray Brouillette, Easter Seals; Andrew Burdan, BIAD; Patricia Martin, United Healthcare Community & State (UHCC); Lenore Reynolds, UHCC; Jamila White, DSAAPD; Bradley Needleman, Maxim Healthcare; Dr. Jane Crowley, A.I. duPont; Kyle Hodges, Staff; and Amber Rivard, Support Staff.

CALL TO ORDER

The meeting was called to order at 2:07pm. Everyone introduced themselves.

ADDITIONS TO THE AGENDA

None

APPROVAL OF MINUTES

A motion was made, seconded and approved for the March 7, 2016 minutes as submitted.

BUSINESS

Concussion Protection Legislation Update

Kyle briefly discussed the Concussion Protection Legislation. The Concussion Protection Legislation is conducted from a current statute of Delaware Interscholastic Athletic Association (DIAA) setting protocols to remove children from play during sport activities. This statute only pertains to DIAA-membered schools and the draft legislation will work on expanding this to community recreational leagues. Meetings were held with Representative Heffernan and Division of Public Health to discuss legislation.

Public Health had questions, concerns and materials on the draft legislation. Kyle stated they will send back responses to their questions to better understand how the draft will work. Public Health, in conjunction with SCPD, will develop regulations. He stated their response will describe SCPD's mandate as the State Primary Brain Injury Council. There is a wide variety of representations by the group including four divisions from the Department of Health and Social Services (DHSS).

The other concerns from Public Health are as follows:

• Will parents be educated about concussions? This is one of the main focus points of the legislation. Kyle stated the bill requires parents to sign a document having information

about concussions. The requirement was taken from the DIAA legislation for consistency with DIAA expectations.

- Who will have authority to remove the child from the field? It states in the draft legislation on-site coaches will have the responsibility of removing the child from play.
- Will DIAA be involved in the process? Kyle stated DIAA has been involved in concussion summits with BIAD and Jane Crowley from A.I.duPont from 2013-2014. He provided Public Health with information on what the bill entitles and how it parallels with DIAA. The only difference being no side-line assessment followed by an immediate return to play is allowed in the recreational league draft. The purpose for the immediate return to play is whenever someone is suspected of a brain injury to take them out and not return them to play. Also, DPH mandates to use scientific knowledge to promote public policy protecting the health of people. Kyle provided an article on current neurological practice with a director from NBA concussion program providing advice on concussions. There are concussions that produce no symptoms until an hour or the next day after the injury occurred.
- Will a concussion information sheet be available electronically that parents/coaches can review and acknowledge? SCPD will provide information to put it online.
- Can coaches or others require undergoing training meet those same requirements online? The bill provides opportunities to complete training online.
- Can the Brain Injury Committee include a concussion specialist? Dr. Crowley is a concussion specialist but BIC can invite a representative from DIAA.

Dr. Freeman stated coaches would be concerned being held liable for a child receiving a head injury during sports. She added coaches have too much responsibility and liability for all the children involved in the game. The coaches would focus more on the field in front of them rather than off field. What if the children are playing with their friends and one of them got hurt because the coaches were not paying attention? She claimed if she were a coach, she would not want to be held liable for all of the children playing the game. Kyle stated coaches would have responsibility for on-the-field play rather than off field. Having the protocol for concussion protection would protect the coaches from liability cases. Dr. Crowley stated teams in recreational sports usually have two coaches on a team. Someone stated the leagues should have a coordinator and a safety person to observe traumatic brain injuries. Kyle stated coaches are to be trained as it is required in DIAA legislation for the high school and middle school levels. Dr. Crowley stated A.I. duPont held a conference for school administrators and coaches at duPont hospital. The coaches spoke about taking a child out of play because of suspected brain injury and the parents wanted their child back in play. Dr. Freeman suggested students could take home a form to the parents that can be followed by a phone call for documentation. Putting forms online can make the process easier for the parents and coaches in the recreational league schools. Dr. Joseph stated her experience has shown that many schools do not have the necessary safety equipment needed. Dr. Crowley added BIAD got involved with a run last year to raise money to give away to any recipients in need for safety equipment in community leagues.

TBI Mandated Services

Dr. Crowley provided a few birth conditions associated with traumatic brain injury. Two of these birth conditions are Autism and Down-Syndrome. She is willing to research more on what the mandated services do for the brain conditions listed. Children with TBI are at risk of having the injury affect the rest of their development. This is beyond early intervention services and is more of an established pact connecting with IEP services. She saw a presentation by a State Education Department and will contact the person that did the presentation. This could be related to birth conditions in children. They spoke about Autism at the early intervention presentation. The earlier that anything can be done for the children with TBI, the better it will be to gather other services. It is difficult to provide the services needed because most children with TBI do not qualify to meet the 25% delay needed in early intervention. However, exceptions are made to children with down-syndrome because they do not progress as other children. Dr. Crowley stated BIC can make the same case for children with TBI to receive early intervention services. It has been stated that medical diagnosis establishes disability. When the children are processed into the medical system, the benefits are not as great and there is little funding including Medicaid. Many dysfunctional families tend to not have many resources for their children.

Kyle asked if these services would be what the State funds when other accessible services are not provided. Dr. Crowley stated that it is mostly a delivery service on top of the other services being provided. Kyle stated it would be better to invite someone to present one at a Brain Injury Committee meeting to discuss TBI mandated services more.

Child Abuse Registry Related to TBI

Children were reported to have a traumatic brain injury involving abuse. Most children abused are under 18 months and this is the highest incidence phenomena in Delaware. Dr. Crowley stated, in working with community pediatricians, it was reported children abused have poor medical follow-ups because they move from one foster family to another. Tracking children with a brain injury related to abuse could be found on the child abuse registry. Dr. Crowley stated if there is a way to attain that information, it would be a great service to help with their developmental delay. Dr. Freeman added that Child Abuse Services are strict when it comes to providing particular information on children being abused. Kyle asked what the main goal is for Child Abuse Registry relating to TBI. Dr. Crowley stated the main goal is to establish a State Service Delivery System to streamline and ordain from an original entry from a child in the system or if they do not enter into the substitute care system, they could keep track of a child for any suspected brain injury and abuse. Dr. Joseph suggested that BIC could receive the list of statistics from DFS (Division Family Services) related to the cases of child abuse reported that is an actual TBI case or a medical diagnosis. Kyle added that he will make a request to DFS for a list of statistics with the type of information needed.

ABI Survivor Camps

Sharon stated Camp BIAD is part of Easter Seals and intended for care givers for respite. It is held Friday-Sunday. Since it was successful in summer 2015, Sharon thought Camp BIAD would return for summer 2016. Easter Seals receives money from the Health Care Fund for respite people with physical disabilities and brain injury. The MS Society loses those available weekends and there are available slots for people with brain injuries. They are renewing for the

State fiscal year and Ray suggested setting up for Camp BIAD. Someone stated last year BIAD and Easter Seals provided vouchers for respite people because they went to camp as respite care givers or survivors. Ray will follow-up with Nancy and Sally to clarify the meaning of what Easter Seals funded the youchers under.

Dr. Crowley stated they want children and adults to benefit from dedicated survivor camps. There are not many camps in Delaware providing respite for children and the care they need. Pediatrics had written an article stating children with TBI will benefit from a summer camp experience with others having similar disorders. Someone stated to check with Nancy O'Malley because of the respite funding was not for adults but for children. The respite fund could be a source of funding for the program. Kyle asked Ray if he is looking into starting a new camp. Ray stated that BIAD can make a request and Easter Seals can work on what is needed to start a survivor camp. Kyle added he and Nancy still are working through details for the camp funding. The respite program was discussed with Easter Seals and Easter Seals will provide the money for it. Dr. Crowley stated hospitals have children patients involved with abuse relating to TBI and can "spread the word" about the program. Ray suggested BIAD, Dr. Crowley, Nancy O'Malley and Sally Price to discuss the process of gathering information from other specialized camps to meet the requirements and where to get funds to support the program. Ray added the difficulty of identifying the children with brain injury can be resolved by researching school IEPs (Individual Evaluation Plans) because teachers would be aware of a child with brain injury.

Injury and Prevention Grant Application Update

Kyle stated that BIAD partnered with Public Health who is applying for a State Violence and Injury Prevention Grant. The grant entails four different aspects and the concussion legislation is a part of it. The DPH will meet the goals of the State Violence and Injury Prevention BASE Program (SVIPP BASE). One of the goals is:

 Goal 1: Protect Delaware children ages five to eighteen from participating in community or travel league sports from damage to the brain caused by inadequate "return to play" protocols.

The goals do not only focus on damage to the brain from "return to play" protocols but, the other three goals focus on sexual violence, child abuse and motor vehicle proponents to decrease injury in general. The TBI aspect of the grant explained in detail the need to have "return to play" concussion legislation in community and school recreational leagues. To express why the protocols are important, it stated in the grant, "A recent survey by Nemours showed that parents and coaches engaged with children in recreational leagues are not familiar with correct protocols for a suspected concussion. As a result many of these parents and coaches would not remove a child from play." The other focus, child abuse, and why it is important was discussed further in this section of the grant. It states "Despite the vision of hospital based primary prevention program and educating parents on infant crying behaviors and TBI, abusive head trauma has not declined but has increased in Delaware." The statement is crossing over not only with the "return to play" policy but with types of issues in child abuse as well. There is data collected by the Child Death Review Commission rating occurrences between 2005 and 2009 were 13 cases of children who died from related brain injury.

In the CDC "Heads Up Materials for Training Coaches" section, the YMCA will educate coaches and parents on safety protocol of children at risk of concussion, learning what to do when a concussion is suspected, reinforce safe play, talk about concussions and make expectations known. After screenings, discussion will be conducted, and outreach programs established. They will work with other community and recreational leagues for targeting a higher risk group - young football players. All of the activities will design culture change, so at the end of the five-year mark, a strong culture of safe play is active in athletic landscapes. They will report to BIC for updates on where YMCA is at in the process of "Heads Up Materials for Training Coaches". A chart was put in the grant to keep track of the goals of this program and steps needed to achieve it. A contract was made to support the YMCA implementing and evaluating TBI prevention strategies for \$49,800 per year. Kyle stated they will not know if the grant will be accepted until August.

BIAD Report

Sharon stated a main focus for BIAD is looking for an Executive Director. She stated how many phone calls she receives and the people who call her that did not know the existence of BIAD. She added BIAD needs to become more involved in reaching out to the Delaware communities. Recently, BIAD met with Christiana High School about disabilities and were able to distribute information of who they are and finding about other services within the state for BIAD to collaborate with. BIAD met with a veterans program in Elsmere to discuss the BIAD group and handed out grant related topics to others at the meeting.

Maria announced Certified Brain Injury Specialist (CBIS) will be sponsored May 21, 2016. CBIS is an important national certification by Brain Injury Association of America (BIAA). Kyle stated Maria might need to contact the MCOs and case managers about the CBIS training. He added from a previous meeting an update of TBI Assessment Pilot through Medicaid and if it is to continue, then BIAD should look into combining the CBIS training with the TBI Assessment Pilot. Maria stated if BIAD has training for BIAA, they can receive a discount for \$260 for all the necessities including the training, books, and certification.

Other Business

Kyle stated Debbie Dunlap asked him how the new CMS rule would affect Peachtree to which he is unsure. The new CMS rule is determining how states provide their home and community based services. Some settings isolate or congregate individuals who may not meet the new CMS requirements. According to the evaluation process, states do not have to comply until March 2019. Currently, all states are identifying their settings required for home and community-based service. The process will take a few years to organize and figure out how those people can receive Medicaid funding. Ron suggested an integrated rule that Veteran Affairs (VA) can build up Medicaid funding. He stated VA programs and day services follow the new CMS rule. The population of frail elderly should combine into community based settings and meet the standards.

ANNOUNCEMENTS

Ron announced Commission of Veterans Affairs is coordinating with the Live VA program and combined with the Delaware Journey Forces (DJF) program. Also, Commission of Veterans Affairs is combining a charter with the VA for many agencies within VA services to become

available. There are 85,000 military veterans residing in the State of Delaware and that is 10 percent of the population. A summit was held to discuss what the status is for Veterans Affairs and updating what each service is doing. It was held in Elsmere, Delaware on April 18, 2016.

There is a Watchmakers Initiative Project that will be created in Middletown, Delaware. This project will provide disabled veterans employment training in watchmaking.

ADJOURNMENT

The meeting adjourned at 3:42 pm. The next scheduled meeting is June 6, 2016 at Smyrna Rest Area Conference Room in Smyrna.

Respectively submitted,

Amber Rivard SCPD Administrative Specialist S: bic/may16min